

Families and Friends of Care Facility Residents (FF-CFR)
Arkansas' statewide parent-guardian association, an all-volunteer organization
Advocating for At-Risk Arkansans with life-long developmental disabilities and
working in support of Arkansas' Intermediate Care Facilities (ICFs), our human development centers (HDCs)

March 13, 2018

Sent electronically
judiciary.house.gov

To: Chairman Steve King
Ranking Member Steve Cohen
U.S. House Committee on Judiciary|Subcommittee on Constitution and Civil Justice

Re: March 6, 2018 Hearing - Class Action Law Suits against Intermediate Care Facilities for
Individuals with Cognitive and other Developmental Disabilities (ICFs)

Dear Chairman King and Ranking Member Cohen:

Please accept these comments from Arkansas' statewide parent-guardian association, Families & Friends of Care Facility Residents (FF-CFR), regarding the March 6 hearing on class action lawsuits brought by federally funded entities against public and private Intermediate Care Facilities for Individuals with Cognitive and other Developmental Disabilities (ICFs). We appreciate that the Subcommittee provided an opportunity for testimonies from families whose loved ones with profound disabilities and their peers have been harmed by lawsuits.

FF-CFR's interest in commenting is that most FF-CFR members have family members who receive residential treatment services at one of five state-operated ICFs. We are grateful that our great state operates a range of service options, including ICF care, for eligible persons with disabilities.

1. Protection and Advocacy Systems (P&As).

Our families are familiar with the protection and advocacy system (P&As), a federally funded program with insufficient independent and objective oversight operating in every state. The majority of Arkansas ICF residents are non-verbal and function in the profound range of cognition impairing their abilities to self-advocate or self-direct their service needs without assistance of others. HDC residents are our state's citizens who are most at risk of abuse, neglect and exploitation. There is no cure for their life-long cognitive deficits / developmental disabilities. The federally funded Arkansas protection and advocacy system, Disability Rights Arkansas (DRA), refuses to represent our families or support the choice of ICF care for our loved ones with disabilities. DRA has brought three federal lawsuits (two of which were class action cases) against our state's ICFs using named plaintiffs from ICFs without notice to their legal

Summary and Request

The comprehensive and devastating reach of the Protection & Advocacy Systems (P&As) and the Department of Justice | Civil Rights Division (DOJ) on at-risk individuals living in ICFs requires a Congressional response. We respectfully request the Judiciary Committee | Constitution and Civil Justice Subcommittee's action in halting the misuse of public funds for agendas of deinstitutionalization by adopting the following policy position:

Protection and Advocacy Systems and U.S. Department of Justice shall not commit federal funds:

- (1) to bring a lawsuit against public or private intermediate care facility (ICF) when the targeted facility is in compliance with the regulations of its funding authority;
- (2) to bring a lawsuit against a public or private ICF when no resident or resident's family has joined in the claims;
- (3) to bring a lawsuit against a public or private ICF when the facility's residents do not have the option to opt out of the lawsuit;
- (4) to enter into *in camera* settlement agreements containing provisions of downsizing and closures of intermediate care facilities without notice to and consideration of facility residents, their families, and legal representatives.

Thank you for the opportunity to submit comments and requests on federal policies which affect our families.

Respectfully submitted,
Families and Friends of Care Facility Residents (FF-CFR)

/s/Carole L. Sherman, Public Affairs Chair
Mother and Co-Guardian of John, age 49, whose brain injuries occurred at birth and who functions as a young toddler

450 Midland Street
Little Rock, AR 72205
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March 13, 2018

Judiciary Chairman and Committee -

In an ICF/ID, the focus is on the resident and their choice. Many residents who reside in an ICF/ID choose to remain there as it is their home, and they have built relationships there. The State of Utah has offered the Home and Community Based Waiver for many years. This gives residents residing in an ICF the opportunity and choice to transition and move out of the facility. There have been instances where residents who previously had applied and been approved to move out of the facility, made the choice later to decline that transition and reside in the ICF/ID.

Class Actions against ICF homes defy the Americans with Disabilities Act (ADA) and Olmstead that honor the individual and make each person's unique needs and choices paramount in accessing accommodations for persons with disabilities. The issues at stake in a class action against ICFs are of a very personal nature, and resolving these questions on a class basis in federal court abridges the rights of class members whose interests are different from those of the named plaintiffs. This could be very costly to family members who wish to protect their loved ones' interests.

It is our position that P&A class actions should not be allowed, as this would go against the interests of P&A's own clients -those class members who want to remain in ICF/ID facilities. We feel there should be oversight of the P&A program to ensure that they are properly carrying out their duties under the law – the duty to protect and advocate the rights of all individuals with developmental disabilities.

ICF/ID facilities provide a necessary service in the continuum of care. We support the decision of residents who make the choice to transition out of those homes into the community. To the residents that choose to remain in our facilities we take all measures to ensure it is a home-like, comfortable and enjoyable residence for them.

We appreciate your time in considering our position in this important issue.

Utah Health Care Association ICF/ID Committee



**THE HOME & SCHOOL ASSOCIATION
OF THE
SOUTHBURY TRAINING SCHOOL**

P.O. Box 872, Southbury, CT 06488
855-200-0480, homeandschoolsts.org



March 14, 2018

To: Chairman Steve King
Ranking Member Steve Cohen
U.S. House Committee on Judiciary|Subcommittee on Constitution and Civil Justice
Via Email

Re: March 6, 2018 Hearing - Class Action Law Suits against Intermediate Care Facilities for Individuals with Cognitive and other Developmental Disabilities (ICFs)

Dear Chairman King and Ranking Member Cohen:

We are writing you in connection with the March 6 hearing on class action lawsuits brought by federally funded entities against public and private Intermediate Care Facilities for Individuals with Cognitive and other Developmental Disabilities (ICFs) on behalf of The Home & School Association of the Southbury Training School. We are very grateful that the Subcommittee is considering VOR's proposal to ensure that individuals named as plaintiffs in such lawsuits are notified of the lawsuit and given the right to opt out.

Southbury Training School (STS) is an ICF operated by the Connecticut Department of Disabilities (DDS). STS has not been permitted to admit additional individuals since 1986 and the majority of STS's residents (presently 206 individuals) are elderly and have profound intellectual disabilities. Many also have severe physical disabilities. These individuals require a high level of care. In addition to a trained staff, doctors, including a psychiatrist, work at the facility, and there is a 24-hour nursing staff.

In 1996, a class action was brought in the US District Court, District of Connecticut, by various private groups which oppose congregate care¹ that named the approximately 700 individuals who then resided at STS against STS, its Director and the Commissioner of the Connecticut Department of Mental Retardation (DMR, now DDS). The plaintiffs made a number of claims regarding the care provided at STS and alleged that the defendants violated federal law by failing to place class members in community-based residential settings.

¹ It should be noted that this is not a suit brought by a federally funded entity. However, the nature of the suit and its result are similar to those brought by federally funded entities and should require notification of all stakeholders and provide them with the power to opt out of the class action.

To: The House Judiciary Committee Examining Class action lawsuits against Intermediate Care Facilities

March 13, 2018

My name is Brad Whitehead and I worked at an Intermediate care facility in Pomona California from February of 1978 to the time of its closure in December of 2014. I hold the very strong opinion that Lanterman Developmental Center in Pomona was closed for the very flawed opinion of many that the best placement for all individuals with Intellectual and developmentally disabled is in the community, without any regard given to the specific needs of the individuals.

I worked at Lanterman as a Licensed Psychiatric Technician and for the first 12 years that I worked there I was a group leader that oversaw the care plans, the day to day schedules and needs of the individuals that were assigned to my care. Always this was done by communicating with each of the individuals personally and their families to develop a plan that best suited the individuals. I was there for assist and direction where needed but did all that I could to encourage as much individuality as possible based on where that person was.

When I first worked at Lanterman we had a very large census of nearly 3,000 individuals that lived in a beautiful setting of over 300 acres and was a hub of activity that was at Lanterman and there were constant opportunities for community experiences as well. I do believe that when I first arrived I identified many of the individuals living there that I felt could benefit from placement into community homes. I also identified that there were many living there that benefitted from the types of services that were only being offered in the setting that we provided, (one size does not fit all). There was also a wide variety of functioning levels at LDC at the time that covered individuals with I/DD from mild, moderate, severe and profound levels of I/DD.

I frequently at team meetings would advocate for community placement for the individuals in my group conversely I would also advocate for continued placement at Lanterman for other individuals usually those with greater needs such as medical, behavioral, those lacking safety awareness or other issues that made them bad candidates of community placement at that and in many cases due to the lack of adequate services for the particular need being offered in the community it would be some time before community placement would be appropriate for the individual. The concerns of the individual's family I believe is also very important in this decision making process, this is a step that I feel is almost not considered at all at this time, because just as I felt as the person who usually spent the most time with the individuals I worked with, I knew that nobody loved or cared for them more than their family.

I believe that the process worked to get those who both wanted and should be moved to the community through an objective process that considers first the individual, next the family and team members that consider the true facts and not a ideology to decide what is best for the individuals.

Thank you,
Brad Whitehead
Temecula, CA

March 14, 2018

Dear Chairman King, Ranking Member Cohen, and members of the House Committee on Judiciary / Subcommittee on Constitution and Civil Justice,

Since the deinstitutionalization of Intermediate Care Facilities (ICF/IID) in Georgia, 504 people died in one year. That being said, I am sure I voice the sentiment of many when I ask that you to please act swiftly and call for a moratorium on deinstitutionalization until we are sure that the services in the community are equal or surpass those in the intermediate care facility. This moratorium includes, but is not limited to, the use of class action lawsuits as a means of leveraging closure and promoting deinstitutionalization.

The Americans with Disabilities Act (ADA) and the landmark Supreme Court *Olmstead* decision interpreting it have improved the lives of millions of Americans with intellectual and developmental disabilities (I/DD) by encouraging community integration. However, people with I/DD are not a homogenous group. Some need greater care for their well-being than can be found in the community. The ADA and *Olmstead* protect this need by recognizing the right of choice for people with I/DD. Unfortunately, the federal agencies that enforce the ADA have adopted an ideological agenda that does not reflect the law's balancing of these goals.

VOR, a national nonprofit organization advocating for high quality care and human rights for people with I/DD, calls on Congress to halt these activities that are harming many severely disabled individuals and make sure the federal agencies enforce the ADA, as written by the Congress and interpreted by the Supreme Court.

Olmstead is often *incorrectly* referred to as a community-only/deinstitutionalization mandate by disability advocates, including the Department of Justice, the Administration on Intellectual and Developmental Disabilities, and the Centers for Medicare & Medicaid Services. They have perpetuated this misinterpretation of the *Olmstead* decision and pursue an agenda of forced deinstitutionalization.

In fact, the Supreme Court in its *Olmstead* ruling recognized the need for a range of services to meet to the varied and unique needs of the entire disability community. But **don't take our word for it**. The best source for what *Olmstead* requires is the decision itself:

(1) Unjustified isolation is discrimination based on disability. *Olmstead v. L.C.*, 527 U.S. 581, 597 (1999).

(2) Community placement is only required and appropriate (i.e., institutionalization is *unjustified*), when — “[a] the State’s treatment professionals have determined that community placement is appropriate, [b] the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and [c] the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities. *Id.* at 587 (emphasis added).

(3) There is an ongoing role for facility-based care: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” *Id.* at 601-602.

(4) A plurality stated: “As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk ‘Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution’ [quoting from VOR’s *Amici Curiae* brief].” *Id.* at 605 (emphasis added).

Simply put, *Olmstead* requires, as plainly stated in the ADA, that people with I/DD receive services and supports in the most integrated setting appropriate to individual needs, consistent with individual choice.

VOR calls on Congress to prohibit federally-funded forced deinstitutionalization by federal agencies contrary to the plain language of the ADA and the Supreme Court’s *Olmstead* decision.

Sincerely,



Ann S. Knighton, Former President and current member, VOR Board of Directors; Co-President East Central Georgia Family Council

Association for Individuals with Intellectual Disabilities

(Formerly Woodbridge Developmental Center Parents Association)

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To: Chairman Steve King
U.S. House Committee on Judiciary Subcommittee on Constitutional and Civil Justice

Re: March 6, 2018 Hearing – Examining Class Actions against Intermediate Care Facilities for
Individuals with Intellectual Disabilities (ICFs/IDD)

Class action lawsuits have been a nightmare for individuals with intellectual disabilities residing in ICFs in NJ..... A nightmare that has caused many individuals with ID to lose their lives.

I am the sister and guardian of a profoundly intellectually disabled 63 year old sister and the president of the Association for Individuals with Intellectual Disabilities, formerly the Woodbridge Developmental Center Parents Association in NJ. Due to a settlement agreement between the state of NJ and NJ Protection and Advocacy, the state of NJ agreed to move 600 residents from NJ's ICFs in 5 years. The governor established a Task Force and two ICFs were closed in 2 years. Mortality rates which were typically 2% per year in NJ ICFs soared especially for the individuals with the most severe and profound disabilities.

The closure process for my sister's home at NJ's Woodbridge Developmental Center (ICF) had a dramatic and tragic impact on the individuals from the ICF and their families. They are not "resilient to change" as some de-institutional advocates would like you to believe. They got sick, had more seizures and many passed away. There were 27 deaths at my sister's ICF in a 3 year period between the announcement of closure in July 2012 and June 2014. This is an increase from the typical 2% mortality rate to 28%. But for those in my sister's cottage #18 where some of the most impaired were living the death rate actually doubled.

I ask the Committee to take two steps to protect the choice of families and guardians and improve the quality of care:



GREEN BROOK REGIONAL CENTER
Family and Friends Association
275 Greenbrook Road
Green Brook, New Jersey 08812

To: Chairman Steve King
U.S. House Committee on Judiciary Subcommittee on Constitutional and Civil Justice

Re: March 6, 2018 Hearing – Examining Class Actions against Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IDD)

We request that Protection and Advocacy organizations and the U.S Department of Justice not use Federal funds to bring a lawsuit against a private or public ICF when no resident, resident's family or guardian has joined in the claims, nor when the ICF's residents do not have an option to opt out of the lawsuit.

I am the sister and guardian of a profoundly intellectually disabled woman, Rosemary. Rosemary has the cognitive ability of a 3 month old. She is small in stature, incontinent, cannot talk, walk or feed herself. She needs to be lifted and moved and will stay where you put her. She cannot cry out when she needs help or is sick. She needs help with every aspect of daily living.

I am also the president of the Green Brook Regional Center Family Association in NJ. GBRC is federally licensed Intermediate Care Facility (ICF). Due to a settlement agreement between the state of NJ and NJ Protection and Advocacy, the state of NJ agreed to move 600 residents from NJ's ICFs in 5 years resulting in the closure of Woodbridge Developmental Center, my sister's ICF. We were the lucky ones and my sister was transferred to another ICF close to me in NJ and was able to adjust to her new home. Many others were not so lucky and succumbed to the trauma of a transfer.

As president of the GBRC Family and Friends Association, I ask the Committee to take two steps to protect the choice of families and guardians and improve the quality of care:

- (1) Require DOJ to Initiate a comprehensive investigation into the cause of the unspeakable number of deaths occurring across the country and suspend activities aimed at displacing fragile Americans from licensed ICFs/IDD in good standing, (see Chairman Goodlatte letter to AG Sessions, 12-6-17) and